

# Welcome

"Down Syndrome: A Parent's Guide to Medical Care" is a series of booklets designed to help you learn more about the general medical needs of infants, children and adolescents with Down syndrome. Each brochure in this series will guide you through the age-based medical recommendations for children with Down syndrome so that you can better work with your child's healthcare provider.

## Always...

Bring up any concerns you may have about your child with your child's doctor.

Tell your child's doctor about any medications or home remedies your child is taking.

Tell your child's doctor right away if you notice any of the following: the way your child walks, uses their arms or hands; a change in urination; any weakness; neck pain or head tilt.

Tell your child's doctor about any heavy breathing, snoring, uncommon sleep positions, frequent night awakening, daytime sleepiness, pauses in breathing, and behavior problems. These could be signs of obstructive sleep apnea.

#### **COMMUNITY RESOURCES**

#### Down Syndrome Association of Central California (DSACC)

www.dsacc.org 4277 W. Richert Ave., #102 Fresno, CA 93722 559-228-0411

# Central Valley Regional Center (CVRC)

www.cvrc.org 4615 N. Marty Ave. Fresno, CA 93722 Fresno: 559-276-4300 Merced: 209-723-4245

#### Exceptional Parents Unlimited (EPU) -Parent & Family Resource Center

www.epuchildren.org 4440 North First St. Fresno, CA 93726 559-229-2000

#### **Parenting Network**

1900 N. Dinuba Blvd., Suite C Visalia, CA 93291 559-625-0384

## National Down Syndrome Society

www.ndss.org 800-221-4602

#### National Down Syndrome Congress

www.ndsccenter.org 800-233-6372 Healthcare Website: www.ds-health.com

#### Break the Barriers

www.breakthebarriers.org 559-432-6292

#### Valley Children's Healthcare – Family Resource Center

downsyndrome@valleychildrens.org (559) 353-8880

#### **CITI Kids**

(Resources for 0-3 years of age) 965 N. Sunnyside Ave., #24 Clovis, CA 93611 (559) 327-8450

Based on the Clinical Practice Guidelines of the American Academy of Pediatrics and the National Down Syndrome Society.

"Health Supervision for Children with Down Syndrome". Pediatrics (Vol. 128, No. 2, August 1, 2011. pp. 393 -406)

"Down Syndrome Health Care Guidelines" National Down Syndrome Society



# DOWN SYNDROME

A Parent's Guide to Medical Care











## **HEALTHCARE GUIDELINES**

**TODDLER AND PRESCHOOL** — 1 to 5 years

#### Your Child's Growth

Children with Down syndrome are at increased risk for becoming overweight. Ask your child to review growth charts with you at each visit. If available, Down syndrome specific growth charts should be used. Consultation with a nutritionist is recommended if your child is overweight.

#### **Gastrointestinal Health**

Children with Down syndrome may have additional problems with their digestive tract. Tell your doctor if your child has problems with constipation (hard or infrequent stools). Additional testing for celiac disease may be indicated if your child is having symptoms. Talk to your child's doctor about additional signs you might observe.

#### **Heart Health**

If your child has been diagnosed with a heart condition, their doctor will continue to monitor for signs of heart failure. Your child's cardiologist (heart specialist) will recommend whether or not antibiotics are needed before any medical or dental procedures.

## **Blood Tests – Iron-Deficiency Anemia**

As with all toddlers, your child's doctor will test for signs of iron deficiency anemia at 1 and 2 years of age. This may consist of a simple finger-stick blood test. If there are signs of anemia, your doctor may consider additional blood testing.

## **Blood Tests - Thyroid Function**

Children with Down syndrome are also at increased risk of thyroid disease. Thyroid function tests should be obtained once every year in this age group, or sooner if there are additional signs or symptoms. Talk to your child's doctor about signs of thyroid problems.

## Your Child's Hearing

A hearing exam should be performed every six months until both ears test normal. Once both ears test normal, hearing exams can be performed once per year. A referral to a pediatric ear, nose and throat (ENT) specialist should be made for any abnormal hearing test.

## Ears, Nose, Throat and Lungs

Respiratory tract infections (infections of the ears, sinuses, nose, throat and lungs), as well as sleep apnea, are more common in children with Down syndrome. A sleep study to evaluate for sleep apnea is recommended by age 4, regardless of symptoms.

#### Eyes

All children in this age group should see a pediatric ophthalmologist (eye doctor) at least once per year.

## Development

Children with Down syndrome are typically delayed in motor, language and intellectual development. As your child grows, you may continue to notice delays in motor skills, language and intellectual abilities. If your child has not established a relationship with the local Regional Center, ask your child's doctor for a referral.



#### **Dental Care**

Dental eruption is often irregular or delayed for children with Down syndrome. Your child's first tooth may not appear until after 1 or even 2 years of age. It is important to establish a routine of dental care even before that first tooth has erupted.

## Down syndrome

## MORE ALIKE THAN DIFFERENT

### **Parental and Family Support**

By now you have probably become more comfortable with your child's care. Don't forget to take of yourself. Staying active and involved will help keep you strong and well-equipped to handle your many responsibilities.

#### **Vaccines**

Children with Down syndrome should receive all routine childhood immunizations, including the seasonal influenza vaccine, unless there are specific contraindications. For children over age 2 with chronic heart or lung disease, the 23-valent pneumococcal vaccine (also known as the pneumonia vaccine or Pneumovax) is recommended.

## Safety

Toddlers with Down syndrome face many of the same safety concerns as other children their age such as choking on small objects and frequent falls. Unlike their peers, they are at increased risk for neck injury. For this reason, trampoline use should be avoided for all children under age 6. Speak to your child's doctor before starting any program that could put your child's neck at risk for injury such as gymnastics or sports with risk of high-speed collision. Your child's doctor may want to obtain a neck X-ray.